

## KNOWLEDGE MODELS AS MEANINGFUL AND LONG LIFE LEARNING ALTERNATIVE FOR RARE DISEASE AFFECTED STUDENTS

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**Abstract.** Rare diseases (RDs) are considered all diseases affecting to less than or equal to 5 in 10.000 citizens, criteria followed by most European Countries. Since most RDs incur disabling conditions, a few patients seldom reach adult life or attend class regularly. However, there are some less serious conditions which are compatible with a better quality of life during childhood and youth and which allow students attend classes in a more regular way. During this period and in these cases, we suggest the possibility of using the software Cmap Tools in order to create knowledge models, so that RD affected students who may miss classes due to their health status, can reach their fellows and follow their teachers' explanations without any particular curriculum adaptation. In the context of a natural science class addressing health and illnesses, we suggest the possibility of using concept maps and V diagrams as tools for getting meaningful and long life learning. Once they learn the basis for creating basic concept maps, RD affected students and their mates may learn some of the symptoms, difficulties of diagnostic, treatment possibilities, foundations and research groups of the most common RDs held in Navarra (Spain), through concept maps. We show an educative intervention in a primary school in Navarra in which one of the students is affected by Treacher Collins and through the presentation of her disease, the rest of the students will get to know the characteristics of this particular disease and will make them be more empathic with her and her immediate reality, making RDs sound less rare. In the other side, by means of this teaching-learning process, RD affected students feel the main characters and also more valuable for society, which increases their self-esteem. By promoting this type of activities, teachers will manage a creative tool which help them in both emotional and professional aspects, since they do not have to adapt the curriculum to a particular student because Knowledge models allow the continuation of the learning process. Finally, the use of Cmap Tools provides items to measure what students knew previously about a particular topic and also helps them appreciate how their cognitive structure has changed and developed regarding their previous knowledge, stimulating a meaningful and long life learning and avoiding conceptual misconceptions.

**Keywords:** Rare Diseases, Knowledge model, Concept maps, Cmap Tools, Meaningful learning, Long life learning.

# 1 INTRODUCTION

## 1.1. Health perspective for RD affected students

According to EUCERD (European Union Community of Experts on Rare Diseases) State of Art Activities 2013, RDs are diseases with a particularly low prevalence; the European Union considers diseases to be rare when they affect not more than 5 per 10.000 persons in the European Union. It is estimated to be between 5.000 and 8.000 distinct RDs, which may be affecting between 6% and 8% of the population through the course of their lives.

In other words, the total number of people affected by RDs in the European Union (EU) is estimated at between 27 and 36 million. Most RDs are genetic diseases, the others being rare cancers, auto-immune diseases, congenital malformations, toxic and infectious diseases among other categories (González and García, 2008) which produce severe disabling conditions, and some patients seldom reach adult life or attend class in a regular way.. Research on RDs is not only scarce, but also scattered in different laboratories throughout the EU due to the lack of specific health policies for RDs and the scarcity of expertise, translated into delayed diagnosis and difficult access to care. This results in additional physical, psychological and intellectual impairments, inadequate or even harmful treatments and loss of confidence in the health care system, despite the fact that some RDs are compatible with a normal life if diagnosed on time and properly managed. Misdiagnosis and non - diagnosis are the main hurdles to improving quality of life for thousands of RD patients.

The RDs Strategy of the Spanish National Health System was approved by the Interterritorial Council of the Spanish National Health System (NHS) on 3 June 2009. It is set within the framework of the Quality Plan of the Spanish NHS which includes, amongst its other objectives, improving care for people with RDs and their families. It represents a consensus between the Ministry of Health, Social Services and Equality of Spain, the Carlos III Health Institute, patient organizations, scientific societies and experts being structured into three parts. The first part, 'General aspects', includes the justification and purposes of the Strategy, the definition of RDs and their situation in Spain covering their historical development and epidemiological situation. The second part, 'Development of strategic lines', sets out the objectives and recommendations included in the following strategic lines:

1. Information on RD (specific information on the disease and on the available care resources)
2. Prevention and early detection of RDs
3. Health care (coordination among health care different levels)
4. Therapies: orphan medicinal products, adjuvant drugs and medical devices, advanced therapies and rehabilitation
5. Social and health care
6. Research
7. Education and training. It is in this seventh strategic line in which our proposal could be implemented.

The third part, 'Monitoring and Evaluation', sets out the process that makes it possible to monitor the proposed actions. The Strategy will act as a framework and a set of recommendations such as: the establishment of the National Registry for RDs, availability of an inventory of services and tests of prenatal diagnosis and derivation protocols for pregnant

women at risk of foetal RDs, raising awareness and recognition of RDs, and promoting socio-health care and research for children under three with RDs. Moreover, the evaluation has also showed that it is necessary to implement actions aimed at collecting and disseminating information and resources available on RDs, to increase training of primary care professionals on suspected diagnosis of RDs and to establish adequate criteria for referral, to improve the availability of basic health information to the teaching staff that attends children with RDs, to develop initiatives of joint coordination and planning for the adaptation of jobs and for the management of the reintegration and continued employment of family members of persons affected by RDs, to carry out initiatives to facilitate keeping persons with RDs in their surroundings such as home care services, home hospitalization, day centers, and so on, to develop integration activities in the community (leisure activities) for those with RDs, and to promote participation of patients associations in participation- decision bodies not only in the area of health of the Regional Government, but also in the area of education.

There is currently a national project managed by the Carlos III Health Institute, called “Spain RDR. Spanish Rare Disease Research Project. Diseases Registries Research Network” which is being developed since 2012 and until the end of 2014 in order to get RDs registries in each Spanish county. It is very difficult to know the exact number of people affected by RDs in Navarra, because they may be registered in several registries from the common hospitals (CMBD, Minimum Basic Data Set) since they may attend several medical specialties consultations until correctly diagnosed, therefore being very likely to have many replicates of the same patient.

According to the Statistics Institute of Navarra (as shown in Table 1), there is a range of handicapped people in the ages of Infant Schooling of 800 inhabitants, of 600 inhabitants in Primary and Secondary Schooling and of 600 inhabitants between the ages of 17 and 24. These potential patients may also be students and they should be our target in order to implement this proposal. All these patients-students may correspond in most of the cases to people affected by RDs and in a range of ages around Primary or Secondary school or University and according to Figure 1, they could approximately be 3.000 people in Navarra.

Units: thousands of people

	BOTH SEXES	MALES	FEMALES
<b>TOTAL</b>	<b>42,3</b>	<b>17,5</b>	<b>24,9</b>
FROM 0 TO 5	0,8	0,4	0,3
FROM 6 TO 64	13,1	7,2	5,9
FROM 6 TO 16	0,6	0,4	0,2
FROM 17 TO 24	0,6	0,4	0,2
FROM 25 TO 34	1	0,5	0,5
FROM 35 TO 44	2,9	1,4	1,5
FROM 45 TO 54	3,6	2	1,6
FROM 55 TO 64	4,4	2,4	1,9
FROM 65 TO 79	13,2	5,6	7,7
FROM 65 TO 69	3,2	1,4	1,8
FROM 70 TO 74	3,8	1,5	2,3
FROM 75 TO 79	6,2	2,7	3,6
FROM 80 AND MORE	15,3	4,3	11

FROM 80 TO 84	6,3	2,2	4,1
FROM 85 TO 89	5,5	1,3	4,2
FROM 90 AND MORE	3,4	0,8	2,6

**Note:**

Data corresponding to cells with less than 1.500 inhabitants must be treated with caution as they may be affected by some sampling errors.

*Table 1: People with limitations or disabilities by age and sex. (Statistics Institute of Navarra).*

It must be taken into account some of the children or young people affected by RDs may suffer very severe conditions incompatible with being able to use TICs or attend classes. However, this proposal is aimed at children or youngsters who at least may be able to understand and learn in a significant level. It will be necessary to work with estimates of the number of people affected by RDs, since there are not official data about the real number of RD affected children and youngsters yet. This is one of the reasons for the creation of a Registry of RDs in Navarra. Although this fact will make this proposal more difficult to be implemented, there is always the possibility to work with RDs associations such as GERNA (Group of RD or Less Frequent Diseases in Navarra). Actually there are 30 RDs included in this association, although there are more RDs in Navarra which are not reflected in this association but it is possible to hear of them because of mass media and special recycling campaigns for RD affected children, such as mobile phones, plastic lids and pens and highlighters.

In spite of the lifelong impact which many RDs entail and the beyond question complexity involved in many of these diseases, we have the moral duty of improving their education considering their right to be educated and take part of a changing society as human beings and develop themselves according to their possibilities, since there are some less serious conditions which are compatible with a better quality of life during childhood and youth. During this period and in cases in which students may attend classes (in person or virtually), we suggest the possibility of using TICs (Technology of Information and Communication) such as Cmap Tools. By using this tool we can facilitate their learning by creating knowledge models, which may help them be more creative and feel more valuable for society, therefore increasing their self-esteem.

## **1.2. Educational perspective for RD affected students**

The educational change that pushes the current context requires a shift in the predominant positive-behaviorist model that favors mechanical rote learning, ideal breeding ground for the existence and maintenance of conceptual errors (González, Morón and Novak, 2001), to another cognitive-constructivist that stimulates meaningful learning to allow students to build and master knowledge, therefore to be more creative and critical (Meichembaum and Biemiller, 1998). Furthermore, the education of the XXI century needs to face a number of challenges: some come from the so-called society of knowledge and information, which can be summarized in a change of an ethic of obligation for another of responsibility, widespread use of information and communication technologies, the so called ICT, and the requirement of a school, in generic terms, of quality, accountable to society and which encourages in students, future knowledge workers, universal literacy, motivation to learn and discipline for

long life learning. Others come from the implementation of the European High Education Area (EHEA) which implies a change in the model of teaching / learning, shaping a new role not only for teachers, but also for students, and affecting the redesign of the subjects contained in the called Teachers Guides (Zabalza, 2004). In this new paradigm, students play an active role not only learning about the product but through the process itself (metacognition). The teacher's responsibility is primarily to create conditions that facilitate the transformation by the student of information in useful, substantive knowledge, which is incorporated well-articulated in its knowledge in the long-term memory.

The assessment in this new educational landscape plays a key role in promoting continuous improvement, consolidating the strengths and correcting weaknesses. Such evaluation should take two dimensions (Novak, 1998): firstly measure what students know and secondly, assessing how their cognitive structure in relation to such knowledge has changed, ie, evaluating the necessary conceptual change (Posner, Strike, Hewson and Gertzog, 1982). It is in this new context in which the teacher classical role has to change. It is a new concept which is on the basis of education where the teaching dimension (emphasis on teaching or taught in) is subordinated to what it is learnt and how students will learn better and will get what they have set as a target. That is to say, education is a concept based in learning and student-centered. Primary and Secondary Schools as well as Universities have to use their potential in order to promote teaching/learning quality, define adequate learning results and point the way to get them. They are institutions that have to integrate all members of society and provide the tools to perform best practices, assume compromises in order to provide society and especially handicapped members a better service (Villar and Alegre, 2004).

The theoretical framework of Ausubel, Novak and Gowin is suited as well as their methodological application through the construction of concept maps (CCMM) and the diagram "V" of Gowin, to undertake educational changes. In general, conceptual maps (CCMM) are diagrams indicating relationships between key concepts or words we use to represent concepts and it is a technique proposed and developed by Joseph Novak (Novak and Gowin, 1988). Concept maps are powerful tools for describing structures of disciplinary knowledge through conceptual hierarchies or meanings, from general to more specific rules clearly and without forgetting the interpretation and explanation of who produces and prepares sense. Graphic icons linked to concepts of the CM can be displayed by clicking on them and then on the writing that appears. Information shall be so displayed. The original map with the associated resources can be accessed via the free download software CMap Tools, of the Institute for Human and Machine Cognition (Cañas, 2004; Novak and Cañas, 2006).

Several research studies show wide evidence demonstrating the great potential of CCMM to improve teaching, both for the diagnosis of students' prior knowledge and for the design and implementation of consistent curriculum and instruction by the teacher.

## **2. MATERIAL AND METHODS**

Our research group (Interdisciplinary in Science Education) of the Public University of Navarra, has implemented a methodology based on modelling knowledge (Cañas, 2004; González, Guruceaga, Pozueta and Lara, 2009; Zabalza, 2004). This work may be applied in

different infant and primary school contexts where RD affected students live and learn together with non-affected students, therefore sharing their knowledge and life experiences. It may especially be used in the approach of a Natural Science Class dealing with the topic Health and illnesses included in several levels of the Primary School Curriculum in Spain.

## **2.1. Design of Concept maps (CCMM)**

The knowledge we have about a topic in a given area is a construction of concepts of that area in a consistent and orderly system (Novak, 1980). These concepts are linked to form statements that are characteristic for each individual. This system can be symbolized by concept mapping. The concept map (CM) is a visual representation of hierarchy and relationships between concepts contained by an individual in his mind. When we speak or write, that hierarchy becomes a linear fashion and it determines meaningful learning because new concepts are assimilated into existing structures rather than remain isolated, stored and eventually forgotten. The concept mapping provides the necessary exchange between teachers and students, revealing what concepts are present in the teaching material and in the student. Learning is sharing meanings (Gowin, 1981) and CCMM make evident those meanings.

## **2.2. Creation of Knowledge Models (KMs)**

A KM consists of a set of CCMM and digitized resources associated therewith, all in relation to a particular topic. It can also be defined as a collection of CCMM linked to a root map representing increasing levels of specific differentiation. Where appropriate, associated resources (photos, documents, videos, etc.) that are designated generically with graphical icons are linked to the maps' concepts. Subordinated CCMM allow the user to navigate through this model. KMs are useful tools to create meaningful learning and avoid conceptual misconceptions by means of the elaboration of CCMM and for their construction, the application of the free software Cmap Tools, created by the IHMC (Institute for Human Machine Cognition) in Florida (Cañas, 2004; Novak and Cañas, 2006) is very useful. This software allows teachers to generate the conditions facilitating students to transform the information in useful, substantive and transparent knowledge, to be integrated in their knowledge structure and in their long-term memory. Students play an active role, not only learning about the product and selecting the information, but through the process itself (metacognition), leaving behind the previous behaviorist-positivist model which favoured mechanical-rote learning and advocating a new model, cognitive-constructivist allowing a meaningful and long life learning as well as promoting critical thinking.

In order to get to know the complicated situation RD affected people must confront until their disease diagnosis and after it, and with the aim to show respect and deference towards some students affected by rare conditions, we suggest the elaboration of a KM, in the context of a Natural Science class addressing health and illnesses in the 5th grade of Primary Education of a public school of Pamplona (Navarra). It could be useful to explain some of the symptoms, difficulties of diagnostic, treatment possibilities, foundations and research groups of the most common rare diseases held in Navarra, especially the one, one of their mates suffer such as Treacher Collins disease. This way students face what some of their mates

suffer and will make them be more empathic with them and their immediate realities, making RDs sound less rare. Also the use of Cmap Tools provides items to measure what students know before and after showing RDs in Navarra, and helps them appreciate how their cognitive structure has changed and developed regarding their previous knowledge.

### **2.3. V diagram or Gowin's epistemological V**

Gowin's epistemological studies (1970) and his concern about educational problems led him to invent the V epistemological. This instructional resource incorporates 12 elements in the process of knowledge construction providing a much broader framework for more effective research reference, and it includes not only the steps of the scientific method, but also the specific knowledge of the concepts, principles, theories and philosophy guiding the research (Gowin, 1981). The V diagram (González, 2008) is a method which help students and educators to analyze the structure and meaning of the knowledge they try to understand (metacognition) and allows the incorporation of new knowledge to the theoretical / conceptual structure the student already has (meaningful learning). According to Novak and Gowin (1988), it is an heuristic device, used to help solve a problem or to understand a procedure. The shape of V, is no accident, but it was designed to house on the left side the conceptual / theoretical (thinking) part and on the right side, the methodological / practical (doing) part, both directed to refer to objects and events in the process of knowledge production.

The V diagram (Figure 1) has been designed in order to answer the following focus questions which represent the objectives of this work:

- Could RD affected students learn significantly by using the software Cmap Tools with no need of a specific curriculum adaptation?
- Will students get to know some of the characteristics of the main RDs in Navarra?
- Will students and by extension, their immediate surroundings (families, teachers and society in general) get aware of the need and requirement that all children must have access to education in spite of their health status?

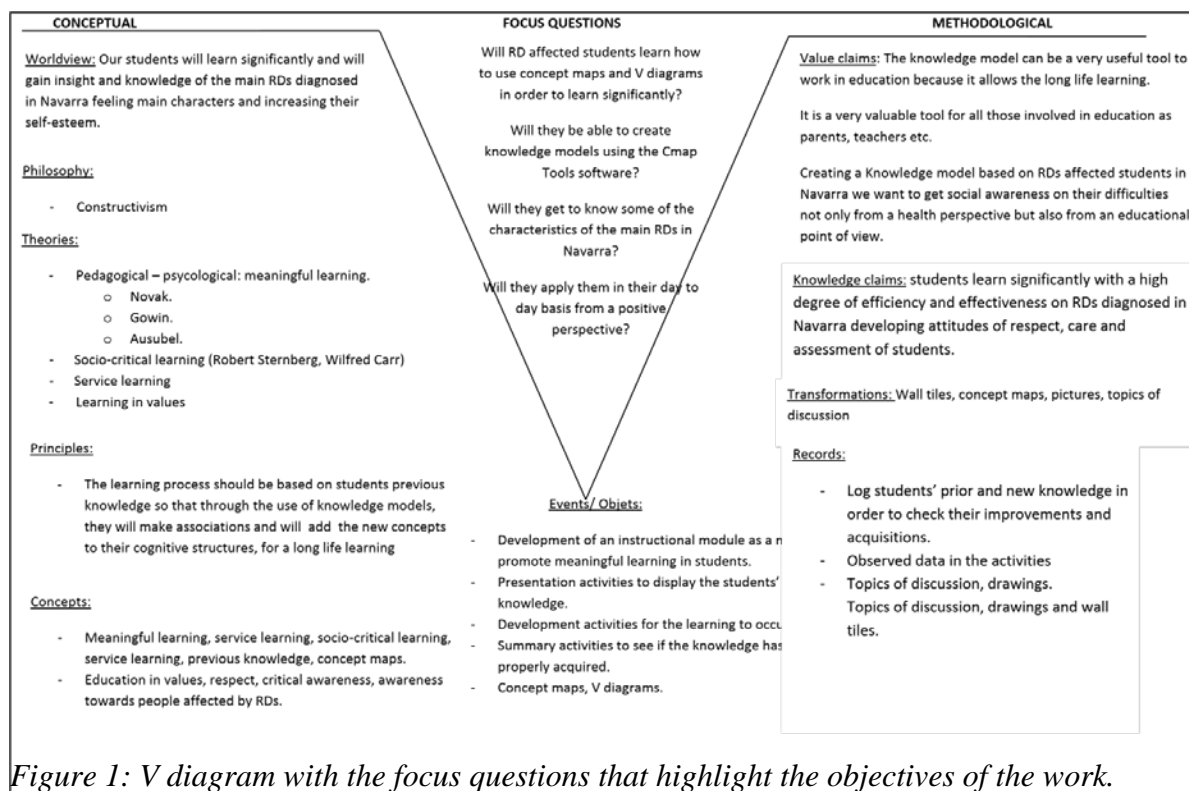


Figure 1: V diagram with the focus questions that highlight the objectives of the work.

Since the enactment of the 1989 Convention on the Rights of the Child (CRC), domestic legislation has been adapting to the principles contained in the Declaration. Although legislation and the legal system of each country might be different, 193 countries have been devoting special measures for their protection, at the legislative and constitutional rights. Within the Rights of the Child four key principles are highlighted:

- 1)Non-discrimination: all children have the same rights
- 2)The interests of the child: any decision, law, or policy that may affect the child has to take into account what is best for the child.
- 3)The right to life, survival and development: all children have the right to live and have a proper development.
- 4) Participation: minors have a right to be consulted on situations that affect them and their views must be taken into account.

By means of this proposal we pretend to give voice to students affected by RDs and try to make them have the same opportunities as any other children to be educated and to live their lives from a wider perspective. In order to fulfill the four key principles of the Convention of the Rights of the Child (CRC), the construction of KMs is provided as a tool available to all children; therefore KMs are built by students and they are examples of meaningful learning and knowledge creative construction (González, 2008; Ballester, 2002).

In the educational intervention carried out in a primary school in Navarra, students from 5th Grade learned about some of the RDs existing in Navarra, and especially the complex situation of one of their mates suffering Treacher Collins.



## **2.4. Educational intervention in a primary school in Navarra in the context of a Natural Science Class.**

An educational intervention was performed in the context of a Natural Science Class dealing the topic of Health and Illnesses. The aim of this intervention was to introduce students to the reality of RDs since one of their mates suffers Treacher Collins syndrome and also to get to know other realities in order to be tolerant and empathic with people with different appearances (Treacher Collins is a syndrome belonging to a group of congenital craniofacial malformation syndromes and characterized by varying degrees of craniofacial deformities).

Teachers planned different activities being the first the visit of the president of the Spanish Treacher Collins Association, belonging to FEDER (Spanish Federation of Rare Diseases) who gave a lecture on the different RDs, emphasizing on Treacher Collins and explained the operations people suffering this disease have to face in order to get a better quality of life. In this particular case, the student suffered several ear operations because of her hypoacusia (hearing loss) and had to wear a special headset. Continuous operations and hospital visits caused the student left the class very often, so she had some trouble keeping up with the class, that coupled with hearing problems. Last year, after the initial evaluation, teachers passed some tests and decided to apply a second cycle ACI (Individual Curriculum Adaptation) with whom she is currently working quite well. According to her tutor's words, the student is "a cheerful, affectionate and participatory girl who loves being the center of attention and helping fellows as long as they need it; it is a privilege to have her in our class".

The second planned activity was to make a presentation in powerpoint explaining characteristics of several RDs, but focusing on Treacher Collins. Students showed respect towards their mate, who is really integrated in class and also a very popular student, since she has appeared in different TV programs and knows famous people who have supported campaigns to raise money for researching on RDs. Also, students showed great interest and posed a lot of questions, which made teachers think future interventions dealing the topic of RDs.

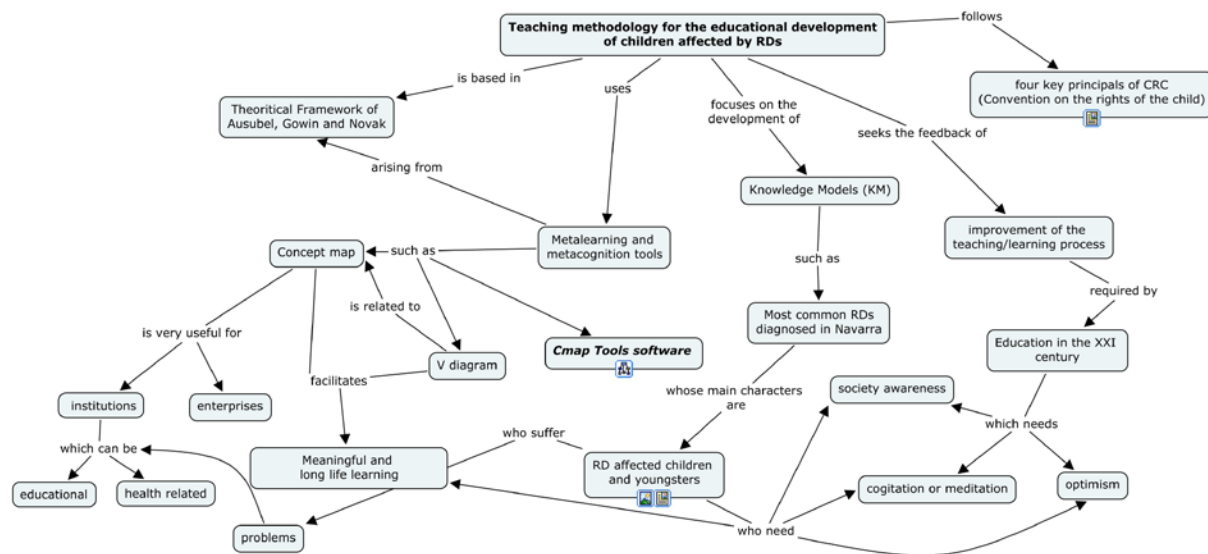
The third activity was reading a book in the post-recess times, as it is after the break where most conflicts occur between peers and it helped them relativize what happened and name their emotions. The book was titled "Wonder: La lección de August" which dealt about a child whose face is different and always walks looking down, in order to hide it from view. With this novel teachers tried to open the minds of students and realize one has always have to be polite when necessary and has to give the hand to the other. Students loved the book and listened carefully, getting a very calm and cozy atmosphere in class.

## **3. RESULTS**

### **3.1. Design of Knowledge Models (KMs) for learning about RDs.**

In this article, we present the KM titled "Teaching Methodology for the education of RD affected children" designed for promoting the learning of Rare Diseases and the difficulties people affected by them must confront throughout their whole life. In this root CM (Figure 2) we show all the instructional tools which may help RD affected students get a meaningful

and long life learning through the construction of Knowledge Models (KMs) and their design using CCMM.



*Figure 2: Root conceptual map titled “Teaching methodology for the educational development of children affected by RDs” which contains other subordinated maps and it is the beginning of the KM. This CM is visible in the following link:  
<http://cmapserver.unavarra.es/rid=1MS406DJH-29L97SQ-2RQ/MAPA%20RA%C3%8DZ%20EERR%20SEECI.cmap>*

The process of building a KM on “RDs in Navarra”, therefore involves the development of CCMM that represent the knowledge of experts on various aspects of the most common RDs in Navarra. The preparation of these maps can be accomplished through interviews with experts. However, the construction of the collection maps is an iterative process in order to ensure thorough coverage of topic maps and faithful representation of expert knowledge (Coffey, Hoffman, Cañas and Ford, 2002; Crandall, Klein and Hoffman, 2006; Ericsson, Charness, Feltovich and Hoffman, 2006; Gonzalez and Zuasti, 2008). Once constructed CCMM, required resources (photos, documents, videos, audio, Web pages, etc.) that best complement and explain the key concepts in concept maps must be selected.

Finally in the CM “RDs in Navarra” (Figure 3) the most frequent diagnosed RDs in Navarra are explained, so that any student can learn about their RD affected mates realities.

As it has been described in previous KMs (Proyecto GONCA, 2003) we decided to create this KM, so that RD affected students would learn on the one hand to use instructional tools for learning significantly, and in the other, they would feel the main characters of the instruction and would substantially increase their self-esteem and social involvement. It aims to develop the knowledge module on the most common RDs in Navarra by editing a CD ROM, navigable for Internet and multimedia resources selected and contrasted linked to different nodes / concepts of CCMM. We expect that one of the objectives is to produce KMs to facilitate the construction of meaningful learning in students, related to basic aspects of their disease, research centers involved, orphan drugs. In order to achieve this objective, students should develop a KM using instructional techniques that contribute to the improvement of the teaching / learning process as CCMM. For the development of this

model, our students should receive a series of materials designed by teachers of the University and the CMap Tools computer program, which can be freely downloaded without cost at the following Internet address: [cmap.ihmc.us](http://cmap.ihmc.us). This program created at the Institute for Human and Machine Cognition (Cañas, 2004) allows students build, share and criticize knowledge based on CCMM.

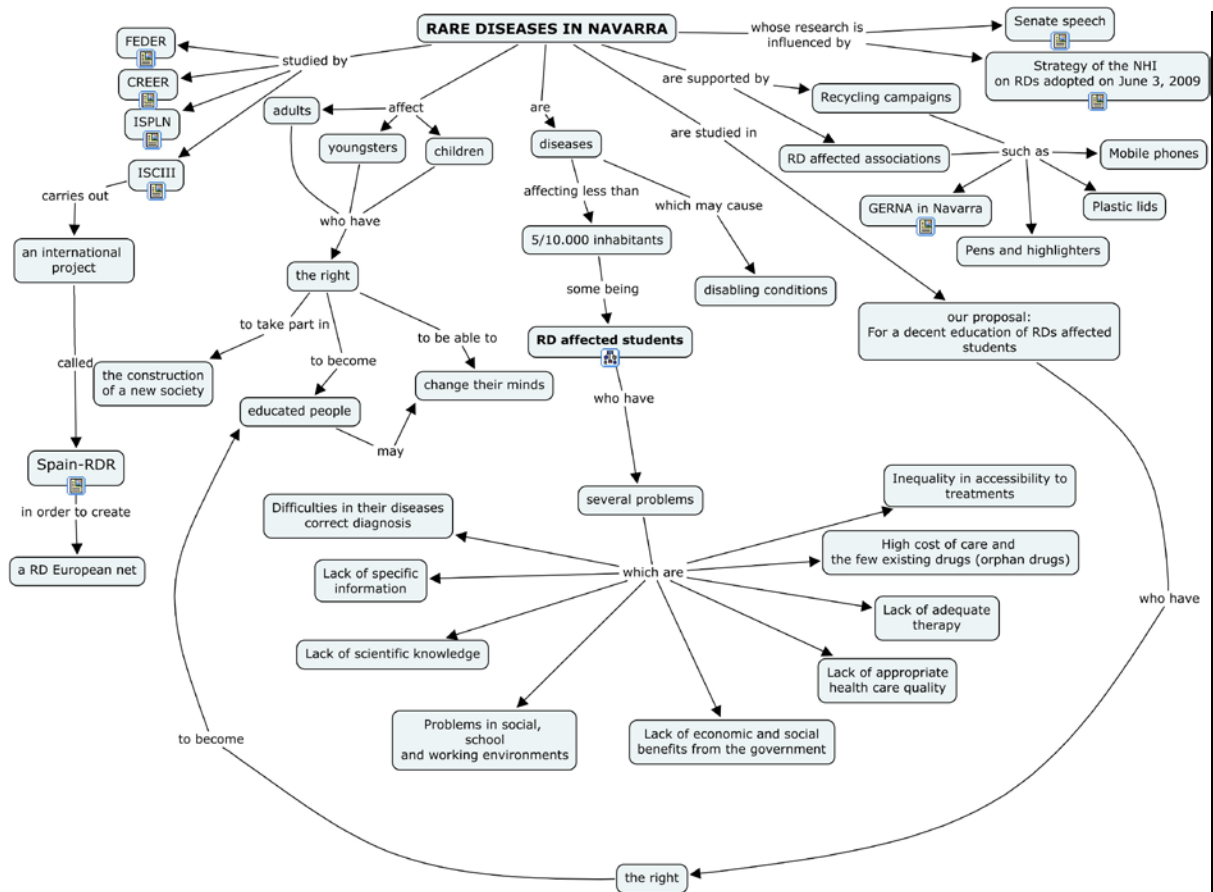


Figure 3: Concept map showing the situation of the most common “Rare Diseases in Navarra”. It is accessible through the following link:  
<http://cmapserver.unavarra.es/rid=1MRR7LZRG-1PZSH-52Y6/Most%20common%20RDs%20in%20Navarra.cmap>

The CM showed in Figure 3, will be designed after obtaining general and specialized information concerning each specific RD. For the organization of the content of the CM, it is recommended to build "base or root maps" which will seek to achieve unity and maintain consistency between the different maps of the same subject. Consequently, the maps that describe the various RDs, reflect a certain archetype, thereby enabling improved visibility and comparability. The news related to RDs appeared in the Internet or in press, can also be collected for later including them as supplementary material and being linked to concepts of the respective CM.

In Figure 4, the CM “RD affected students in Navarra” is shown as well as subordinated maps describing different types of RDs diagnosed in Navarra. It is possible to

navigate through the constructed KM about the “Teaching methodology for the education development of children suffering from RDs”, using the CM as interface.

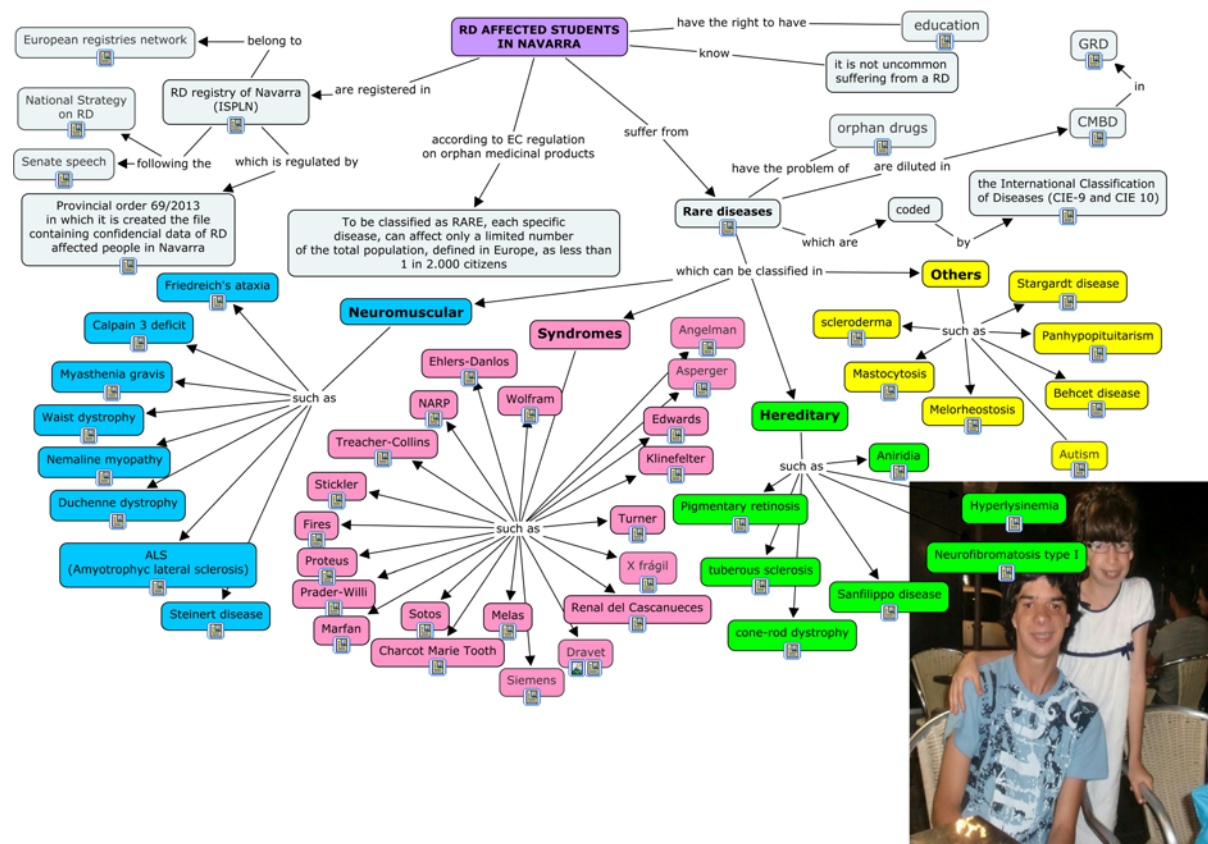


Figure 4: Concept map showing the various RDs diagnosed in Navarra with several deployed resources that correspond to a specific rare disease (Treacher Collins) and a photo of two affected students. This is the link for access:

<http://cmapserver.unavarra.es/rid=1MRV9XY53-CSF4H-5714/RD%20affected%20students%20in%20Navarra.cmap>

To summarize, if clicking on the map from Figure 2, which represents the KM of the "Teaching methodology for the educational development of children affected by RDs" and contents the more general and inclusive concepts, we can use it as interface, being possible to navigate by clicking on the concept "RD affected children and youngsters". This concept leads to the CCMM of Figure 3 "RD diseases in Navarra". If clicking on the concept "RD affected students", the CM of Figure 4 "RDs affected students in Navarra" gets displayed. A number of details obtained by clicking the corresponding generic icons and graphics linked to concepts are also observed. Through clicking on any of the RDs displayed, students can learn the main symptoms and characteristics of each disease. In this case, they would learn about Treacher Collins which is the disease affecting their mate and which association can be observed in this link: <https://asociaciontreachercollins.wordpress.com/>

#### 4. DISCUSSION

According to UNESCO (United Nations Organization for Education, Science and Culture), education is a fundamental human right, essential to exercise all other rights. It promotes freedom and personal autonomy generating significant benefits for one's development. However, millions of children and adults remain deprived of educational opportunities, in many cases because of poverty. However, there are also cases of education deprivation in countries of the First World, especially for those people, handicapped, who are not able to attend most classes because of their health status. In this group, we would be talking about RD affected students who suffer the consequences of their health problems and hospital admissions and in the most fortunate cases, these students are subjected to individualized educational program (ACI) but in other more serious conditions, students do not attend classes and are out of the educational system. It is up to governments to fulfill their obligations, both legal and policy reasons, relating to the provision of quality education for all and more effective implementation and monitoring of educational strategies.

Through this article, we try to point out to the complicated world of RDs and those who suffer them, with special emphasis on the affected students. Through an immediate need identified in a Primary school in Navarra (Spain), teachers were faced with the requirement to explain the situation of one of their mates who suffered from a RD. For that, they planned an educational intervention through the development of three main activities, and due to the positive response and the interest showed by students, a future proposal to put into practice in a near future was designed.

The intention was to implement instructional tools that could help RD affected students continue their education that could be used alone or together with the ACI (Individualized Curriculum adaptation) and that in turn, would also help the other students get to know about RDs and the reality affected people have to confront and accept and integrate RD affected students as any other mate. For this reason, we designed a proposal after the mentioned positive educational intervention which had previously showed a real interest by students. In this proposal we show how to create KMs, based on information that the student must turn upon a previous assessment and transform it into substantive and useful knowledge into their cognitive structure as an alternative to the ACI. Each map contained in the KM, is derived from the foregoing, powering their own meanings. The KM is like a building which has been built based on meaningful learning and it is original, because although the information was there, reorganizing it and its consequent re-conceptualization has led to the development of an original model, open to any improvements, by some students able to add value to it with new information relevant to them and having an organized mind. CCMM help identify, understand and organize the concepts we plan to teach and also help to specify the relationships (propositions) necessary for the understanding (González, 2008). CCMM prepared by the student are an effective way of knowing what he/she already knows. As a key principle in education is to start considering what the learner already knows, to investigate is a very important task in any educational initial step. The experience of connecting new information to existing knowledge in a meaningful way by the development of CCMM constructing the building of knowledge through KMs, causes positive feelings on students and when they recognize their own cognitive structure as the foundation of an educational fact, the meaning of this experience changes in a powerful and lasting way. The V diagram identified the key issues that led to the birth of this proposal and some of the focus questions

have been answered through this work but others still need future work to be done. The focus questions indicated in the V diagram were the following:

- Will RD affected students learn how to use CCMM and V diagrams in order to learn significantly?
- Will they be able to create KMs using Cmap Tools?
- Will they get to know some of the characteristics of the main RDs in Navarra?
- Will they apply them in their day to day basis from a positive perspective?
- Will students and by extension, their immediate surroundings (families, teachers and society in general) get aware of the need and requirement that all children must have access to education in spite of their health status?

Through the educational intervention, students got to know the characteristics of the main RDs in Navarra, especially the one affecting their mate, Treacher Collins syndrome and once they know the difficulties RD affected students confront because of their health, they get aware of specific educational intervention requirement, which could be the implementation of CCMM and V diagrams for a meaningful learning in subjects such as Natural Science, in order to avoid ACI or at least, or at least to improve it. Further research is needed in order to confirm the substitution of ACIs by KMs and V diagrams but evidence to support these value judgments are the results of other investigations (Albisu , San Martín and González , 2006; Ballester, 2008).

This approach forms the basis of the design and implementation of the topic of RDs in the context of a Natural Science Class dealing Health and Illnesses in a primary school. The aim is that students achieve meaningful learning through the construction of KMs, based in the particular case of a RD affected mate in class. This way, students affected by RDs may continue the lessons without a special ACI, and the rest of the students, learn about the reality of their colleagues being more empathic.

The KMs built by students facilitate meaningful learning and creative construction of knowledge through a process that is open to facilitate students' long life learning. Every student, enabled or disabled has the right to learn in a meaningful way for the rest of his/her life (Convention of the rights of the child, 1989). Finally, it is remarkable the fact that education is a powerful tool that allows children and adults who are socially and economically marginalized to go out of poverty through their own efforts and participate fully in community life.

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